

DOWN SYNDROME

This fact sheet has been written by parent carers for parent carers.



What is Down syndrome?

Down syndrome is a lifelong genetic condition. It is caused when a person inherits an extra chromosome (chromosome 21). People with Down syndrome tend to have some characteristic physical features, as well as having a level of learning disability, which may be mild, moderate or severe. But as with any condition, each person will be affected in differing ways. In the UK it is estimated that around 750 babies are born with Down syndrome every year.

Characteristics of Down syndrome

When a baby is found to have certain physical characteristics associated with the condition, it may lead to further tests and a diagnosis of Down syndrome. In most cases, this tends to happen shortly after birth. There are many services that offer support to parents whose child has recently been diagnosed with Down syndrome – some contact details are listed overleaf.

There are some other health issues associated with Down syndrome and you will want to talk to your community paediatrician about this. However, it is important to remember that although there is an increased likelihood of your child having related health conditions, he or she may not be affected by them and most are routinely treatable. With the right support, the long-term prospect for the majority of children with Down syndrome is positive in terms of participation in school, work and community life.

Types of Down syndrome

- **Full trisomy 21 Down syndrome** – the most common form of the condition accounting for almost 94 per cent of all cases.
- **Translocation Down syndrome** – a rarer form of the condition that affects about 4 per cent of people who are diagnosed with Down syndrome, where an extra piece of chromosome 21 attaches itself to other chromosomes.
- **Mosaic Down syndrome** – the least common form of the condition accounting for just 2 per cent of cases, where only some cells have an extra copy of chromosome 21.

Types of treatment

There is no 'cure' for Down syndrome, but there are a number of therapies and interventions that can help people with the condition to lead a full life:

- **Audiology and Ophthalmology** – regular assessments with an Audiologist (hearing) and an Ophthalmologist (sight) are important as people with Down syndrome are more at risk of hearing loss and sight problems.
- **Cardiology** – regular check ups with a cardiologist may be advised as a cautionary measure as people with Down syndrome have a slightly higher risk of heart problems.
- **Diet** – children and adults with Down syndrome can be more susceptible to weight gain. A dietician can advise on any adjustments that may need to be made.
- **Early Intervention** – early intervention programmes have shown to be effective in helping all children with learning difficulties. A home-based package of support in education, speech therapy and



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physiotherapy will help maximise your child's development.

- **Occupational Therapy (OT)** – can help your child develop their hand skills and can identify solutions to help your child develop their independence with every day tasks such as dressing and eating and drinking.
- **Physiotherapy** – important intervention to help a child develop and maximise their range of movement and posture.
- **Speech and Language Therapy (SALT)** – specialist support provided by a therapist to help build language and communications skills.

Ask about

- **Information, Advice and Support (IAS)** – Amaze supports families of children and young people with SEN and disabilities in Brighton and Hove. We have a helpline, publications and a website. We also run workshops and courses and can offer one-to-one support with EHC planning and making DLA and PIP claims. Call Amaze on: **01273 772289** or visit: **www.amazebrighton.org.uk**.
- **Compass Card** – a free leisure discount card administered by Amaze for 0 to 25 year olds registered on The Compass who live or go to school in Brighton and Hove or West Sussex, or who are looked after by social services in these areas. Call Amaze on: **01273 772289** (Brighton and Hove).
- **Independent Support** – Amaze's Independent Supporters provide extra advice and support to young people and parent carers who are going through the process of getting an EHC Plan in Brighton and Hove and Sussex. For Brighton and Hove Independent Support, call: **01273 772289**. For Sussex Independent Support, call: **0300 123 7782**.
- **Making a claim for DLA** – if your child's care or mobility needs are significantly greater than the needs of their peers you may be able to claim Disability Living Allowance for them. Find out more at: **www.gov.uk**. Amaze can give you advice and practical support with making a claim. Call the helpline on: **01273 772289** or email: **helpline@amazebrighton.org.uk**.
- **Integrated Child Development and Disability Centre (Seaside View)** – diagnosis and support for your child. Assessments will usually be via a health or education professional but you can contact Seaside View directly on: **01273 265780**.
- **T21 Brighton & Hove** – a parent support group for children and young people with Down syndrome and their families. The group shares information and provides children's activities. For more information, call Emma on: **07810 567626** or Fiona on: **07801 692362**, or email: **emma.parker148@btinternet.com** or **fionafromcutiebrighton@hotmail.com**. You can also find T21 Brighton & Hove on Facebook – just send a request to join.
- **Worthing Kids & Dapper Snapper** – Worthing-based charity who have strong connections with families of children with Down syndrome. They run a number of projects and services including drop-ins for parents and children, a youth club and swim school. Visit: **www.wkds.org**, call: **07570 768893** or email: **info@wkds.org** for more information.

Further reading and useful links

- **Brighton and Hove's Local Offer** – comprehensive online listing of all maintained (special and mainstream) schools in the local area and non-maintained schools that are attended by Brighton and Hove children. See **www.brighton-hove.gov.uk/localoffer**.
- **Down's Syndrome Association** – **www.downs-syndrome.org.uk**.
- **Down Syndrome Education International** – **www.dseinternational.org**.
- **National Deaf Children's Society (NDCS)** – has information about Down syndrome and hearing loss. Go to: **http://www.ndcs.org.uk** and click on 'Family Support' or call their helpline: **0808 800 8880**.

